

HOME -BASED AND LONG-TERM CARE

Home Care Issues and Evidence



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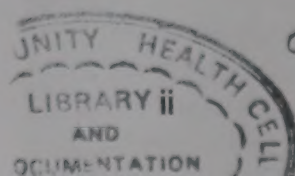
Home Care Issues and Evidence

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for the World Health Organization
1999

WORLD HEALTH ORGANIZATION
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Health Care Systems

Health Care with the Health Care System

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Health Care Systems

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Preface:

This document presents an overview of the major issues in home- and long-term care based upon the available published evidence to date (Summer 1999). A more detailed review of the issues and an annotated bibliography can be found in Document WHO/HSC/LTH/99/1.

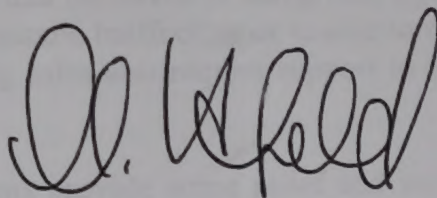
The next two decades will see dramatic changes in the health needs of the world's populations with non-communicable diseases as the leading causes of disability. Increases in the older population by up to 300% are expected in many developing countries. In addition, HIV/AIDS, TB and lymphatic filariasis continue to be a major cause of disability (and death). Everywhere there is a steep increase in the need for long-term care.

These changes require a very different approach to health sector policy and health care services since a disease-specific approach, alone, is no longer appropriate. The one common denominator resulting from these demographic and epidemiological changes is **functional dependency and the growing need for care to manage everyday living**. Rising health care use and spiralling costs have everywhere led to a trend and the necessity to treat patients in the home. Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health including care toward a dignified death. Home care services can be classified into preventive-promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories. This paper primarily addresses long-term home care.

Acknowledgements:

I would like to acknowledge Betty Havens without whose vast knowledge and expertise this project would never have been possible. She has broad international experience and many of us from developing and developed countries alike, know her as an inspiring mentor, teacher, researcher, advocate and friend.

I would also like to acknowledge Ms Elizabeth Tornquist for her editing and Ms Linda Burgess for formatting and the final preparation of the document for publication and distribution.



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The following passage is taken from the 1990 Human Development Report (p. 104). It is a statement of the importance of human capital in the context of the world's development.

Human capital is the sum of the skills, knowledge, and health of a population.

The report also states that the world's development is not only a matter of economic growth, but also a matter of human development. It is a matter of improving the quality of life, of increasing the opportunities for all, and of creating a more just and equitable world.

These changes require a new approach to development. It is not enough to focus on economic growth alone. We must also focus on human development. We must invest in education, health, and social services. We must create a more just and equitable world. We must ensure that the benefits of development are shared by all.

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I would like to acknowledge the many people who have helped me in the preparation of this report. In particular, I would like to thank the following individuals for their support and assistance:

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INTRODUCTION

Home care is generally envisioned as having one of three objectives: to substitute for acute care hospitalization; to substitute for long term care institutionalization; or to prevent the need for institutionalization and maintain individuals in their own home and community. The overall goal is to provide high quality, appropriate and cost-effective care to individuals that will enable them to maintain their independence and the highest quality of life. Virtually all studies have found home care to be associated with higher quality of life and some studies have found it to be cost-effective. Cost-effectiveness has been found most frequently in home care that substitutes for acute care and less frequently in home care that substitutes for long-term institutionalization. Cost-effectiveness is more difficult to demonstrate in home care programs that maintain individuals in their own homes when they need care but are not candidates for institutional care. In this paper, the major emphasis is on home care that is designed to enable recipients to live in their familiar communities in the company of their network members, and to continue to enjoy the best possible quality in their lives.

Several issues must be resolved if home care is to become, or continue to be, a viable community care program. Two of these issues are closely inter-related; they are the potential for exhaustion or "burnout" of caregivers in the informal sector and the potential for burnout of formal caregivers.

The available evidence suggests that families and informal network members want to continue to care for their members who require care. Further, persons who require care continue to want to remain in their own homes and communities.

However, the level of care required by home care users has increased and is likely to continue to do so in the foreseeable future; therefore, both the amount and intensity of care provided by informal and formal caregivers are also increasing. The question is whether caregivers can continue to provide the care required without themselves becoming consumers of health care. There is little point in straining the capacity of caregivers to such an extent that we wind up with two users of the health system rather than one (Haug, 1985). This makes provision of support to informal caregivers by both the formal and informal sectors even more important. However, it should also serve as a warning that the stress of caregiving by those in the formal sector can also become so great that they become ineffective or unable to continue to perform their jobs. Thus, those in formal caregiving roles also require support to continue providing high quality care.

While many formal home care delivery systems provide some relief and support to informal caregivers, the amount, frequency and duration of this support vary widely. When support to the informal caregiver is not both an explicit goal and a legitimate function of the formal system, this support often begins too late in the process of delivering service to delay or prevent caregiver burnout.

Support to formal caregivers varies even more than with informal caregivers. Many service deliverers provide no support at all to their employees. The idea that those employed in the long-term home care sector might require periodic relief leaves has received very little attention. Leave-time, with or without pay, is given occasionally, but it is not an expectation of either employers or formal caregivers. Use (and abuse) of sick time, requests for shift changes and high turnover rates, especially in times of high unemployment, may be indicators of inadequate or no support to formal caregivers. Lack of employment stability among formal caregivers reduces continuity of care and thus becomes a problem both for home care users and their informal caregivers, as well as the delivery system. Inadequate in-service training and failure to provide emotional support to staff who are caring for difficult, rapidly deteriorating or terminally ill users of the system are other indicators of inadequate support to formal caregivers. High quality employment practices should be used to address these stress indicators before formal caregivers cease to provide care, or worse, become clients, or patients themselves.

The majority of both institutional and community long-term care users are women, as are the vast majority of both formal and informal caregivers. As a result, the issues surrounding long-term care are women's issues as well as health care issues.

The lack of studies focusing on women who are formal caregivers or voluntarily care for non-family members and who are also informal caregivers to family members "in their free time" is a serious deficit. We know almost nothing about these women and the burden of caregiving and nothing at all about the impact of their dual caregiving roles on their own health.

Other important issues of home care include the impact of new technologies, both low technology such as the use of appropriate body mechanics to enhance physical caregiving potential and "high" technology such as electronic aids. Important issues beyond the boundaries of the health care system include unemployment and changing amounts of poverty, which may increase the pool of personnel available to provide informal care or decrease the care user's ability to pay for uninsured or voluntary services.

The first section of this paper deals with home care policy; the second, with home care services. The third section deals with policy and service issues related to formal and informal caregiving; the fourth, with home care in cases of specific diseases. The final two sections deal with home care staffing, and with home care as a component of some other part of the health care system.

Home Care Policy

Most of the policy literature is not based on research but has been developed from program or service experiences; thus, it tends to be based on descriptive material. Much of the literature is made up of government documents with a minimum of interpretation. Though these articles are largely anecdotal and idiosyncratic, they reflect the state of knowledge in the

field of home care policy. And unlike much of the rest of the home care literature, the policy sources tend to take a forward-looking perspective.

Providing an overview of home care policies around the world is a daunting task and no authors have accomplished this. While the policy pieces purport to be international, most cover relatively few countries. The only overview article that is specific to home care policies (Hedrick et al., 1986) comes to the conclusion that better studies are required to determine whether home care is effective across multiple dimensions and to address the cost-effectiveness of home care.

Most of the articles that compare the policies of different countries also deal with issues related to the cost and cost-effectiveness of home care, and two articles concentrate entirely on financing issues (Henrard et al., 1995; Freedman et al., 1996). Two other articles (Jamieson, 1992; Lesemann et al., 1993) present comparisons of several countries and a number of policy concerns. In a different vein, Chappell (1994) notes that in European and North American countries home care research, and hence the home care literature, has produced more in the areas of program development and service delivery than in policy development or analysis. She concludes that our current knowledge is not as much help to policy makers as they would wish. Clearly, more uniformity in terminology and in policy analytic strategies, based on more thorough policy research, is needed by the home care field and also desired by policy makers.

Not surprisingly, the largest body of topical policy material is about caregiving, by both informal caregivers, usually family, and formal caregivers, such as staff. Informal or family care dominates this policy issue (Doty, 1986; Gubrium et al., 1990; Hanley et al., 1991; Herrman et al., 1993; Tennstedt et al., 1993; Wuest, 1993). Several authors argue that formal home care is not a substitute for, but rather a complement to informal care. The major themes that emerge from the literature are the durability of informal caregivers and warnings that policy must support informal caregivers and that, without adequate support, informal caregivers may not be able to sustain the current levels of care being provided. While some of the policy articles (Burbridge, 1993; Gordon, 1997; Hayashi et al., 1994; MacAdam, 1993) focus on labour market issues, they address few of the employment policies of home care service delivery organizations. Corporate policies that enable employees to be both primary informal caregivers and employees and policies that preclude this are addressed by Gilhooly and Redpath (1997). However, they do not address the concerns of formal caregivers who are also providing informal care.

A large number of policy documents are specific to individual countries or groups of relatively like countries. Most of this work tends to simply describe the home care policies in these locations, including home care funding and financing issues, ideological bases for home care, gender policies, and models of home care. These models include the maintenance and preventive model, the long-term care substitution model and the acute care substitution model of home care identified in the Introduction (Health Services Promotion Branch, 1990; Sorocean, 1995).

Two Scandinavian articles make unique contributions to the policy literature: one (Waerness, 1987) addresses home care and community care policies from a feminist perspective; and the other (Joffe, 1989) deals with policy issues arising from the principle of economies of scale, that is, the ability to provide care to large numbers of persons at a lower per person cost than when the same care is provided to a small number of persons. The policy issues that surround migration of older persons (Meir et al., 1993) is addressed by one article. Several policy sources discuss the historical and cultural context of health care generally, and of home care, specifically; one of these articles (Oshomuvwe, 1990) makes a plea for improving the data used for policy making.

Home Care Services

Home care services and service delivery issues are a major focus of this paper. In some cases home care services are placed in the broader context of health care services. Very few articles, however, are based on research or evaluation; most are descriptions of service and service delivery experiences. One notable exception is a European research-based article (Kempen et al., 1991), in which the authors report on a research strategy that could be considered for use in many jurisdictions. The vast majority of these materials present "best practice" examples of services and service delivery (Jamieson, 1991; Hutten et al., 1996; Clark, 1996; Havens, 1990; Ghei, 1980; Morris, 1983). Although they tend to lack evaluation content, they reflect exemplary practice in the field of home care services.

Many sources describe innovations in home care services (Monk, 1993; Monk et al., 1989), the development of home care service delivery mechanisms (Monk et al., 1995; Quinn, 1995; Feldman et al., 1996) or the delivery mechanisms themselves (Burack et al., 1995; Keating, 1995; Simon et al., 1993; Clinco, 1995). Three articles deal specifically with case management (Shapiro, 1995; Challis et al., 1986; Halton, 1992), and one deals with the development and use of a "single entry" system in long-term care (Shapiro, 1993). The authors provide information that will enable others to determine whether or not to use similar mechanisms and if so, how to go about developing their own local examples of these mechanisms. Despite the typically idiosyncratic nature of home care financing, three helpful sources (Hughes et al., 1987; Halamandaris, 1990; Henrard et al., 1995) take a more generic approach and therefore should be worth considering in other locations. Similarly, although laws and regulations tend to be quite idiosyncratic, the Israeli Community Long-Term Care Insurance Law (Brodsky et al., 1997; Brodsky et al., 1993) is one that deserves serious consideration by other jurisdictions.

Several authors deal with the attitudes toward (Rowland, 1992) or satisfaction with (Braun et al., 1987) home care and with home care workers (Eustis et al., 1992; Eustis et al., 1991), which are important in both the development and evaluation of formal home care programs. Two other important and under-reported aspects of home care are predictors for use of home care service (Shapiro, 1986) and the characteristics of those receiving home care (Wilkins et al., 1998).

A few articles describe the role of non-governmental organizations (NGOs) in providing home care (Schmid, 1993; Mann, 1997; Habot et al., 1985) and one article (Rosengarten et al., 1990) describes the evolution of an NGO that collaborated with a municipal government home care program. Another article provides excellent documentation for anyone attempting to develop an NGO home care service using volunteers (Thornton, 1989). In one innovative example (Nixon, 1990), volunteers "bank" their volunteer hours to be "spent" if they need care later. Several authors emphasize the strengths of the family and family support in well established home care programs (Facchini, 1993; Mercadante et al., 1993; Lingsom, 1989).

Most of the sources dealing with home care service delivery in both developed and developing countries describe urban experiences. However, there are a few explicitly rural examples of best practice home care experiences from Nigeria (Peil, 1991), Japan (Shimada et al., 1993; Takeda, 1973), Canada (Havens et al., 1993) and the United States (Berke, 1992; Dansky et al., 1998; Newhouse et al., 1987).

Given the heterogeneity and cultural diversity of home care recipients, it is surprising that only one (Blanter et al., 1995) specifically stresses the importance of providing culturally sensitive services. Likewise, given the importance of information for both appropriate uses of services and compliance with treatment regimens, it is surprising that only one article (De et al., 1985) has specifically addressed the importance of providing correct and relevant information. All of the sources dealing with either natural (Chubon, 1992) or man-made disasters (Lang, 1997; Lang et al., 1997; Vespa et al., 1995) and situations in which man-made disasters exacerbate natural disasters (Moore et al., 1993; Godfrey et al., 1989), identify the vulnerability of the old, the very young and those who are disabled or ill. It is unfortunate that little concrete information on meeting the home care service needs of these groups is presented in these articles. One author (Zarb, 1993), however, describes many of the issues of ageing with a disability.

Formal and Informal Caregiving

Caregiving and caregivers, especially informal caregivers, are the focus of much of the literature on home care. The discussion here focuses first on formal caregivers, then on informal caregivers, viewed from the traditional perspective of informal caregivers as unpaid family members and friends. This discussion is followed by a review of the current policy debates on whether or not to pay informal caregivers. The fourth section focuses on informal caregiving for persons suffering with dementia, since this tends to be reported separately from the more general caregiving literature. Because so much of the home care literature involves caregivers, several other sections of this paper also deal with caregivers. For example, informal caregivers are discussed in the sections dealing with disease-specific home care. Further, the section on home care staffing contains material on formal and informal caregivers.

Formal Caregivers

Much of the literature focussing on formal caregivers reflects policy-makers' fears that formal care will replace informal care. Two sources (Tennstedt et al., 1993; Lingsom, 1992) that are representative of the literature addressing this concern point out that formal care complements or supports but does not replace informal care.

High turnover rates among caregivers are a frequent problem in the formal home care sector. Two authors (Surpin, 1988; White, 1994) have reported on programs that were successful in reducing turnover. Surpin described a home care "worker owned" co-operative that delivered paraprofessional home care services and reduced worker turnover. The co-operative empowered the formal paraprofessional caregivers through their collective ownership. White described a consortium of agencies that used free pre-employment training and worker placement services provided by the consortium in exchange for a commitment on the part of the worker to continue working within the consortium agencies for at least six months. Again, turnover was reduced within the consortium. One article (Zimmer et al., 1985) reports on a randomized controlled study of a formal caregiver team project in which clients who were randomized to the new team approach had more positive outcomes and were more satisfied with their care than the clients who received usual care.

Informal Caregivers

The literature on informal caregiving and caregivers is voluminous. Most of this literature is descriptive, locally sensitive and almost exclusively from the highly industrialized nations. This is ironic given the much greater reliance on informal caregiving among the least industrialized nations. Virtually all aspects of the informal provision of care by family and other members of the social support network have been documented somewhere. The few sources that are discussed here provide only a sketch of informal caregiving. Family is an important aspect of informal caregiving, and community or neighbourhood networks are another. For example, one article (Adamchak et al., 1991) emphasizes the importance of intergenerational exchanges, describing the support that flows from elders to other generations. Another source (Apt, 1998) stresses the importance of keeping elderly persons involved in their communities, including as caregivers. At the other end of the spectrum, Uhlenberg et al. (1998) identify grandchildren as potential caregiving providers or resources.

It is well known that many elders have very small support networks, and lack of support is sometimes identified as a major risk factor for institutional long-term care. Interestingly, one article (Takeuchi et al., 1994) notes that decreased functional mobility increases the likelihood that elders will live with family members; but this is clearly impossible when elders have small or non-existent family networks.

A frequent concern in the informal caregiving literature is caregiver burden or burnout. In one study (Snyder et al., 1985), the authors specifically identify the health problems of caregivers as a concern. Another issue for many informal caregivers is the necessity to balance the competing demands of their labour force activity and their informal caregiving

(Stone et al., 1990). Thus, Wilson et al. (1990) appropriately identify the importance of “robust” support networks for caregivers themselves; in other words, caregivers need support in order to maintain their caregiving roles.

The Issue of Payment for Informal Caregivers

One of the most comprehensive articles on the issue of payment for informal caregivers is a recently released Canadian government report by Keefe and Fancey (1998) which clearly outlines the policy implications of the three most common forms of caregiver compensation. These three forms of caregiver compensation are direct compensation, indirect compensation and self-managed or consumer-directed programs. Another article (Sipila, 1995) highlights the relationship of the social system to the forms and acceptability of compensation. Clearly, paying for informal care is becoming an important issue, and the forms of compensation used in any given jurisdiction are based on the health and social welfare policies and the social welfare and philosophical systems of that jurisdiction.

While focusing primarily on indirect compensation, Sipila and Simon (1993) present the pros and cons of paying informal caregivers, while Glendinning (1990) describes the financial dependence and interdependence that result from paying or not paying informal caregivers. Glendinning notes that when caregivers are not paid, they are likely to become financially dependent on care receivers; but when caregivers are paid, care receivers tend to become financially dependent on caregivers. More importantly, Glendinning demonstrates that informal caregiving is not “free” care since caregivers incur costs in providing care whether they provide it themselves or pay others. One article (Vinton et al., 1996) indicates that caregiver compensation is used primarily to pay for basic household necessities. Using a more sophisticated analysis, Keefe and Medjuck (1997) identify the long-term economic consequences for caregiving women and recommend that both public and workplace policies take these consequences seriously when considering changes in policy or practice.

It is usually assumed that paying informal caregivers means paying family members; however, Thornton (1991) reports on a program that pays volunteers to provide care to non-family members. This British study is particularly interesting because it concludes that nominal pay fosters and maintains a sense of volunteerism that is actually threatened by paying more than a nominal amount. Stone and Keigher (1994) offer an overview of U.S. policies related to providing financial support to family caregivers based on the Family and Medical Leave Act of 1993. The latter legislation may provide an interesting example for other industrialized jurisdictions.

A self-managed or consumer-directed compensation program, also known as the Independent Living Movement in North America, is the third form of informal caregiver compensation (Doty et al., 1996). This model may foster integration of the formal and informal care systems but is generally more acceptable to younger, physically disabled adults than to older and more frail home care clients.

Informal Caregivers to Persons Suffering with Dementia

Generally, informal care of dementia sufferers is viewed as sufficiently different from other kinds of informal caregiving that it is seldom discussed in articles on general caregiving. Therefore, this division has been maintained there. Many sources identify a “value of care” dimension, which arises from societal norms, as the underlying motive for continuing to care for family members with dementia. However, Assada (1991) suggests that breakdown in family caregiving to persons with dementia is inevitable.

A large number of authors have identified characteristics of caregivers to dementia victims that should be treated as danger signals or risk factors for inability to continue to providing care. Wackerbarth (1998) includes caregivers’ emotional and physical health and health status, amount of sleep, privacy, subjective burden and disruption to everyday activities as risk factors. Many other authors report that gender, age and socio-economic differences in social networks are significant predictors of ability to continue caregiving; and Hibbard et al. (1996) demonstrate that these characteristics are important for identifying vulnerable caregivers.

Many authors are concerned about the networks that provide support to informal caregivers of dementia sufferers particularly in order to combat social isolation. This has been identified as especially important among caregiving daughters (Bledin et al., 1990). Among spousal caregivers (Commissaris et al., 1995), access to a general practitioner and a durable social network have been identified as reducing stress and maintaining care in the community. Some authors suggest that social isolation may continue even after the dementia sufferer is placed in an institution (Van de Ven et al., 1983) and may continue to be problematic for the caregiver even after the death of the family member (Bodnar et al., 1994).

Issues with Specific Diseases

The literature on home care for specific illnesses generally integrates formal and informal care because the focus is on the disease, not on caregiving or service organization. Thus, while the first part of this section continues the discussion of dementia, here the disease (almost exclusively Alzheimer’s disease) is the focus. The second part of this section deals with home care for persons with HIV/AIDS. The final part of the section deals with home care provided to victims of a broad range of miscellaneous diseases.

Home Care with the Dementing Diseases

Much of the home care literature that deals with dementia focuses on caregiving, both formal and informal. However, some sources focus on the dementing diseases rather than on caregivers; for example, one review article (Keady, 1996) reports on the dementing experience. Several articles (Newens et al., 1994; Smith, Jr., 1988; Williams et al., 1995) stress the importance of physicians to the families of Alzheimer’s patients. In the longitudinal study reported by Williams and associates, the emphasis is on the changing needs of the

family as the disease progresses. Two articles (Riva et al., 1997; Ineichen, 1998) present approaches to developing community resources for demented elderly persons and their caregivers.

Home Care with HIV/AIDS

There is a substantial body of literature on home care for HIV/AIDS patients. This section presents the context of HIV/AIDS, and discusses special services, the design of palliative care teams, training issues (generally involving training indigenous persons to deliver home care), informal care for HIV/AIDS patients and a few miscellaneous issues.

The epidemic in rural areas is far from contained (Wawer et al., 1994); this information should lead to home care policy and services decisions to deal with patients in these geographic areas. As early as 1992, Decosas and Pedneault noted the spread of HIV/AIDS to women and children. Recently afflicted persons are among the most marginalized groups in the population, and with these people prevention strategies are largely ineffective. These groups include injection drug users, very young gay men, indigenous peoples and vulnerable women, often very young girls (Albert et al., 1998). Unfortunately all of these vulnerable groups are ill-served by home care policy and programs. In the case of HIV/AIDS, the evidence of need exists, but policy, programs and public opinion lag behind that evidence.

Within the broad topic of special services, most of the work to date has been site specific but capable of broader application. For example Chandwe (1994) points out that by integrating home care services to HIV/AIDS patients with services to patients suffering from other diseases (i.e., generic home care), the stigma attached to the disease is avoided. Hernandez et al. (1994) describe the development of a non-profit health centre in which professional services are largely donated in order that services may be made available to those with extremely low or no incomes. This strategy should be applicable to other low-income areas and with other diseases. Ssemukasa and Apio (1994), following rigorous scientific analysis, recommend the use of indigenous, no cost herbal remedies rather than high cost pharmaceuticals in low-income rural areas. Ong et al. (1994) used a day centre to create a supportive atmosphere within which to provide treatment and develop mutual aid and support among patients.

Reilly et al (1994) have reported on "Respite House" which operates 24 hours a day with a co-ordinator and 80 volunteers to provide respite care. AIDES, a specialized agency (Rossert et al., 1994), is successfully delivering care, in collaboration with standard home care services, to HIV/AIDS patients, 60% of whom live alone. The ability to respond to those who live alone is unique, but should be replicable in other jurisdictions and with other diseases. Another source, (Chipfakacha, 1997), identifies the high risk to traditional healers of contracting HIV/AIDS and describes methods to reduce this risk.

Most of the articles that discuss specialized HIV/AIDS palliative care teams report that the teams originated from hospitals and are physician led. Two sources (Frederiksen, 1994; Pereira et al., 1994) report virtually the same results except that the teams were led by nurses. The major differences among these examples are the staff-to-patient ratios, the total number of patients involved, and the percentages of patients who died during the study period.

The most frequent reports on training involve training of local and indigenous persons. For example, in one programme (Byngire et al., 1994), one local person per village is trained as a counselling aide and functions to link the hospital or medical centre with the patient in the local community. A "train the trainer" model is used to extend the training to more communities and surrounding rural areas. Several sources (Katabira et al., 1994; Onyango et al., 1994; Schietinger et al., 1994) stress the importance of neighbours and urge that neighbours be trained along with family members and persons with AIDS (PWA).

In the HIV/AIDS literature, informal care is frequently referred to as informal support-which differs from the general literature on home care. Another difference is that few sources on HIV/AIDS specifically address informal support whereas in general home care the material on informal care is voluminous. Perhaps the most important example of caregiving descriptions in the HIV/AIDS literature (Moller, 1997) identifies AIDS in Africa as the "grandmothers' disease". This results from the fact that the burden of caring most often falls on grandmothers, who frequently are the only ones left in the villages to care for both the victims of AIDS and their children who may also be victims of the disease. Several sources identify the lack of resources available to informal support providers of persons with AIDS. Others identify the importance of providing social support to the supporters of HIV/AIDS victims and recommend including a social worker on the formal caregiving team. Perreault et al. (1994) indicate that the caregivers of AIDS victims come to the formal system very late, as do many informal caregivers; but unlike other caregivers, they often do not recognize or do not respect their own needs for support.

In June 1999, UNAIDS released a report based on the experiences of six diverse community programs which highlights the importance of generating or enhancing community support for care of persons with AIDS and their families (UNAIDS, 1999). These programs were successful in part because they mobilized communities and involved persons with AIDS in the programs.

Mercer et al. (1996) note the limited knowledge about HIV/AIDS in high-risk areas, including rural areas. Another source (Nfila, 1994) notes that patients themselves and their families often do not support home-based terminal care. All of the articles on cost (Tramarin et al., 1992; Tramarin et al., 1994; Afheldt et al., 1993) demonstrate that home based care of those with HIV/AIDS is cost-effective. However, one source (Sichone et al., 1994) reports that provision of home care is not realistic in the extremely poor rural areas of developing countries, where securing food and maintaining proper hygiene continue to be compromised. This is an excellent example of why the population health model, which examines the determinants of health, is critical to the development of community health programs and policies.

Home Care with Specific Diseases Other than Dementia and HIV/AIDS

This section deals with several diseases, including diabetes, stroke, and multiple sclerosis, among others. In articles on diabetes, home care is usually discussed only as part of the policy and service concerns to address prevention and control. However, Markell and Friedman (1990) address caregiving within the context of dealing with the care of diabetic patients with end-stage renal disease. Unfortunately, while they identify these patients as needing a "consortium" of formal caregivers, they virtually ignore the patients' families. Similarly, Soni Raleigh (1997) describes home care as an extension of the care performed by primary and community health care professionals.

In contrast, one article on elderly stroke patients (Yoon, 1997) reports that family care is related to maintaining the quality of life of these patients. Another article on stroke (Silliman et al., 1986) places the effects of caregiving on the health of caregivers of elderly stroke patients within a policy context.

Two articles dealing with multiple sclerosis (Aronson, 1997; Dewis et al., 1992) address the issues of family caregiving for persons with MS, which they say are not the same as the issues in general informal caregiving. Family caregivers are shown to be necessary in the homes of persons with MS to prevent institutionalization. The authors also discuss how the formal care system can better support family caregivers.

An ethnographic study in northern Canada on chronic obstructive pulmonary disease (Miles-Tapping, 1994) shows that home care, even in the relatively adverse conditions of isolated communities, in a harsh climate, provides a better quality of life in a culturally appropriate setting for those with COPD. Home care also both improves health and reduces the economic hardship experienced with lengthy hospitalizations or other institutionalization. While the literature on vision impairment is becoming more common, only Orr (1987) has described how home care providers can help identify the early stages of vision loss. This author also suggests ways that home care workers can be more effective by reinforcing independent-living skills among their visually impaired home care clients.

Home Care Staffing

The literature on staffing deals primarily with issues that are related to staff of formal home care services. Dealing with these issues will make the difference between developing or maintaining viable home care services and allowing the care needs of frail or ill persons to overwhelm our caring capacity. Havens (1995b) distinguishes between the expectations and behaviours of clients and families and those of staff since understanding these distinctions is essential to developing appropriate home care policy, and maintaining, delivering and evaluating both informal and formal care. The first part of this section addresses training, broadly conceived to include both pre-employment and continuing education of staff, training of informal caregivers and clients. The second part deals with staff-related concerns in Adult Day Care and Respite Care, which diverge somewhat from other components of home care.

The next two parts address the concerns of nurses and physicians, respectively. The final topic is the use of technology, primarily "high" technology, including information technology, in home care.

Training Issues in Home Care

Five types of training are addressed in the home care literature: training of professionals, supervisors, para-professionals, family, and the home care clients themselves. The major emphasis is on training para-professionals, which includes training of indigenous workers, typically volunteers.

Although a vast quantity of training literature exists, little of it explicitly includes home care and even less is multidisciplinary. However, Banoob (1992) addresses the multidisciplinary training needs of the developing countries for home care and other forms of services designed for use by the rapidly increasing elderly population in these countries. The author, drawing on examples from Romania, Barbados and Kuwait, stresses that training should be short-term and include physicians, nurses and social workers, at the very least. Banoob further notes that an integrated, short-term training strategy has been adopted by the International Institute on Aging (INIA) in Malta. Another article (Nordin et al., 1992) identifies geriatrics as an "essential subject" in the education of physicians. This article demonstrates the importance of training health care professionals to understand and provide care to the rapidly increasing elderly population, especially in the developing nations. A related issue is the challenges in training home care and other health care workers to use "high" technology appropriately (Kaye et al., 1991). While "high" technology assistance with home care is still relatively rare, it is an emerging area that requires far more attention, especially in regard to training, staffing and ethics. Home care, like many other health care fields, runs the risk of adopting these technologies without adequately preparing staff, informal caregivers, clients and the general public for their appropriate implementation. Research about all of these aspects of training is sorely needed but sadly lacking.

Training by supervisors in home care programs is primarily seen as a mechanism for retaining direct home care service providers, most of whom are para-professionals. Retention rates have been shown to improve when supervisors are involved more extensively in in-service and on-the-job training (Burack et al., 1995; MacAdam, 1990). MacAdam stresses that for supervisors to be successful with an expanded training function, they too require enhanced training.

As noted at the beginning of this section, training para-professionals is the predominant theme in home care training. This training includes skills training, training in affective or interpersonal relationships, and training of indigenous workers, typically volunteers. One relevant issue is the ageing of the population, which is rapidly occurring in the developing nations. The need to respond quickly can best be accomplished by training para-professionals to work in home care (Michel, 1998). Recruiting and training middle-aged women as home care workers has been demonstrated to be more successful than training younger, more mobile workers. The older women tend to stay with the same client longer and their overall retention

rate is better (Clinco, 1995). Higher rates of musculoskeletal injuries exist among home care workers than among other female workers; and the most frequent cause is lifting clients (Ono et al., 1995). As a result, Ono et al. recommend specific training for these workers in body mechanics and lifting.

The importance of positive interpersonal relationships between home care workers and their clients is well documented; however, this affective domain of home care is seldom a component of the training of home care workers. Positive interpersonal relationships are important both to the client and to the worker's job satisfaction which, in turn, enhances client care. Agency supervision and support are also important in fostering positive interpersonal relationships (Chichin, 1992). The potentially negative outcomes of positive relationships include the risks of worker exploitation or decreased client control. Eustis et al (1991) argue that this underlines the necessity to include interpersonal relationships as a component of training. As would be expected, positive interpersonal relationships are more important to direct service providers than to indirect service staff (Kaye, 1986).

Material about indigenous workers in home care frequently identifies these workers as volunteers, rather than staff; however, this does not diminish the importance of training these people. One aspect of volunteer training (Gezairy-Hussein, 1995) is legitimizing the traditional cultural value of keeping older people at home, which is usually best accomplished through training local community volunteers to serve as informal caregivers to elderly persons in their family homes. Training indigenous people as staff, not as volunteers, that is, training them as nursing assistants or para-professional home health workers in their home communities (John et al., 1996) is another important way to ensure the maintenance of traditional cultural values. The training of rural community members as volunteers who care for HIV/AIDS patients, although initiated to combat the stigma surrounding these patients, also ensures that patients and their caregivers receive care and assistance consistent with their culture and customs, which vary in different local communities. The "train the trainer" models, addressed earlier, contribute to these goals (Schietinger et al., 1994).

It is disappointing that so little literature has dealt with the training of family caregivers to care for their chronically ill older relatives. Training the family, or a family member, to develop and use problem-solving skills in caring for the family member has been demonstrated to be very important to (Houts et al., 1996). The lack of material about the training of home care clients is also disappointing. However, there is one very complete guide (Worcester, 1990) to the appropriate training of elderly home care clients, which includes aspects of vision, hearing, cognition and response time.

When asked why there is so little available material, those who provide direct care, supervise that care or train those who provide care say that they are too busy "doing" to undertake research or to write articles. Nevertheless, the gaps in both the "best practice" and the research literature must be filled if we are to move the field forward and continue to deliver high quality home care for those who need it. Without more documentation, we also run the risk of having every program repeat the failures of others because they cannot learn from those who have tried but not documented a particular strategy. This is a time consuming and wasteful misuse of limited resources, especially human resources.

Adult Day Care and Respite Care Issues

Adult day care or day programs are a form of collective or group home care that is appropriate for some, but not all home care clients. Attendance at an adult day program may provide social opportunities that are otherwise unavailable to the isolated elderly home care client (Gutman et al., 1993; Watanabe et al., 1994). The programs may also serve to monitor the care of a client (Morris, 1988) and they may provide a "break" for informal caregivers, especially spouses or other elderly caregivers (Gutman et al., 1993). Respite care is designed to provide the caregiver with a rest, a break, and the opportunity to conduct necessary business or to socialize with others. Both of these are seen enabling the informal caregivers to continue providing the majority of day-to-day care to elderly home care clients and to delay requests for residential placement or nursing home entrance. The timing of respite services is especially important for enabling informal caregivers to maintain care and prevent caregiver fatigue, "burnout" or illness (Yamada et al., 1994). Because these services are used only periodically and the timing of that use is, of necessity, individualized, the programs must be very flexible (Tataru, 1997). At the same time, because these services are typically delivered in a congregate setting, certain fixed costs and minimum staffing exist regardless of whether the services are used by only one or by many clients, at any given time. As a result, these home care services represent staffing challenges.

The most typical form of respite care is the temporary use of institutional placement for respite (Grasel, 1997). Those suffering with dementia constitute the most prevalent clients, and adult daughters or daughters-in-law tend to be the primary caregivers of these clients. It is difficult to understand why so many potential clients do not take advantage of this service. Cox (1997) found that users tended to be caregivers of clients with poorer cognitive status who felt less anxiety but experienced greater burden. Users reported fewer hours of informal assistance and fewer behavioural problems than non-users. Thornton (1989) provides a very useful "best practice" example of respite care that was developed and continues to be based on the use of volunteers to provide respite services. This program has substantial potential to be used as a model for a broad range of home care services in locations where few formal services and service providers are available.

Nurses in Home Care

Nursing personnel are usually recognized as the backbone of formal home care programs. As a result, most jurisdictions are concerned about projecting the number of nurses needed for home care. Okamoto's (1997) innovative use of secondary data sources makes this article important. Using available data to project future need for home care personnel is much more efficient and less costly than gathering data in the field. While Okamoto's data sources may not be replicable across jurisdictions, the approach can be usefully repeated.

Hospital nurses' caseloads are sometimes extended to include home care clients when the nurses follow patients as they are discharged from the hospital (Bull, 1994; Hill, 1995) in order to prevent readmission. In one home care program (Cowart et al., 1987), nurses are

known as “taxi nurses”, because they serve an area that is within 30 minutes, by taxi, from the private hospital that initiated home care services in the mid-1970’s.

Sophisticated home care provided by nurses is sometimes referred to as complex care. The earliest “high” technology home care involved peritoneal dialysis (Brunier et al., 1996); as the age of home dialysis clients has increased, complexity has also increased, because of the large number of comorbid conditions among these clients. Another example of complex homecare is the management of pain (Kemp, 1996), especially when this is accompanied by a substance-related disorder. The particular challenges of providing palliative care in rural communities (Morgan, 1997) include coping with complex and often under-resourced situations; this requires extremely sophisticated nursing performance. The ethical issues confronted in delivering home care are an ongoing concern of nurses and other personnel. In one “best practice example (Skipper, 1992), a visiting nurses’ organization established an ethics advisory committee to address these issues. This well documented model holds substantial potential for replication.

Nursing roles in home care typically include assessment, case management with a focus on family caregiving, provision of needed services for chronic care and episodic acute care treatment, preventive care, collaboration with physicians and links to the broader health system (Burns et al., 1989). Many nursing interventions are designed to promote or improve the health of family caregivers (Swanson et al., 1997) because home care nurses are well positioned to monitor and intervene, to prevent or reduce problems for the client or caregivers. The goal of home care assessment is to enable elderly clients to achieve or maintain the highest possible level of functioning (Keating, 1995). Continued assessments are necessary for both those who continue to receive care at home and those who eventually enter a nursing home (Schirm, 1989). Assessments may also be used to enhance compliance with drug regimes (Kluckowski, 1992), by improving the client’s and caregiver’s understanding of the medication, its functions and benefits, and by incorporating aids to adherence.

Physicians in Home Care

Relatively little material focuses on physicians in home care. The physician’s role is primarily one of patient oversight (Grieco, 1991; Koenig, 1986; Koren, 1986); thus it is important to incorporate house calls in the training of physicians. In addition, hospital-in-the-home or home hospitalization programs (Stessman et al., 1997) that provide sub-acute or episodic acute intensive care in the home rather than in a hospital cannot function without the regular in-home attendance of a physician. Inadequate compensation for physicians in home care (Koren, 1986) continues to occupy some physicians, though this issue is seldom raised by low paid para-professionals or unpaid volunteers. To address the compensation issue and maximize the limited time that physicians spend discussing home care with their patients, Pannill proposes using a screening instrument (Pannill, 1991) to identify high-risk patients who will then receive a more complete multi-disciplinary assessment.

Technology, especially “High” Technology in Home Care

“High” technology, including information technology, may not yet be a pressing concern in the developing nations. However, these applications will become more common and may be diffused even more rapidly in the developing world than has been the case in the more developed nations. Training is a major concern in the adoption of “high” technology (Leader et al., 1988; Mehlman et al., 1991). Information technology holds much promise as a tool for home care, but it requires training and places new demands on clients and caregivers, as well as staff.

The introduction of “high” technology to home care is not without problems; for example, such technology potentially leads to “medicalization of the home”, thereby threatening the quality of life for the client or informal caregivers (Leader et al., 1988). Concerns about “high” technology and home care clients and their families led Handy (1989) to say: “High-technology home care cannot and should not merely be care of the technology (the ‘machines and tubes’) at home; rather, it should emphasize the care of the patients and families who are receiving the technically complex therapies.” (p. 46).

“High” technology in the home includes peritoneal dialysis (Brunier et al., 1996), pain management, the most prevalent form of “high” technology home care (Bedder et al., 1991), home intravenous therapy, which is frequently used with HIV/AIDS patients (Afheldt et al., 1993), use of infusion pumps (Greif et al., 1995) and parenteral nutrition at home (Smith et al., 1993).

The use of computers by informal caregivers of dementia sufferers to seek information, communication and support for decision making is effective and relatively common among those who have a computer available to them (Brennan et al., 1991). While a relatively small proportion of all caregivers now have computers, many more are expected to use them in the future. Personal health data management systems can be the basis for computer-based home care support and monitoring programs (Ishikawa et al., 1995). Emergency response systems (Vlaskamp, 1992) and the Lifeline social alarm systems (Premik and Rudel, 1996) are important forms of information technology, and these devices may become integrated into the technologically sophisticated homes of the future, sometimes known as “smart houses”.

Premik and Rudel stress that for technology transfer to be successful, a social innovation process must support the transfer of the technology.

Home Care as a Component of the Health Care System

This final section examines home care as a component of some other part of the health care system. When home care is treated as a component of ambulatory care or of community care, it is seldom well integrated within that larger portion of the health care system. By contrast, when home care is seen as a part of hospital care, it is usually tightly integrated into

the hospital system; in many cases, it is difficult to identify where hospital care ends and home care begins.

Ambulatory Care

According to the literature, home care is often mentioned merely as a part of existing ambulatory care (Miralles et al., 1998; Kaplan et al., 1995) or as a desired component that has not yet become available (Al Shammari, 1997).

Community Care

As with ambulatory care, there is very little indication that home care is integrated with community care, even where home care programs are relatively well developed. Generally, the integration of home care with broader community care programs is a goal or, at least, recognized as desirable. The most thorough overview of community-based long-term home care is provided by Clark (1996). The rationale for including home care within community care is that most persons and their informal caregivers prefer long term care to be community-based (Buss, 1994). The need for adequate and appropriate housing is a major concern for those planning and delivering community care. As a result, Arnold et al. (1993) recommend better co-ordination between community care programs and housing investment programs.

Though older persons usually prefer care in their own homes and community, Al Shammari and associates (1997) report that while physicians in Saudi Arabia thought almost half of their elderly hospitalized patients could be cared for at home, just under half of these patients and over two-thirds of their relatives preferred institutional care. Based on this preference, the authors recommend finding more cost-effective facilities to provide culturally acceptable alternatives for these patients and their families.

Community care is related to community development, as several "best practices" illustrate. A classic article (Hildebrandt, 1994) describes how a community development process was used in one local area to enable residents to develop a range of community care responses to the needs of older members of their community. Another article (Leutz, 1976) describes the indigenous caregivers that exist in virtually all neighbourhoods and suggests that formal community care agencies should search out and involve these local caregivers in delivering services to elderly persons. Such partnerships can serve vulnerable persons who are hard to locate and even harder to reach with traditional formal services; also, these partnerships enhance compliance with care plans. For example Chan (1993) noted that those over 50 were very much over-represented among the volunteers in these services. Seniors, as the volunteer providers of local community services, are also cited by Havens et al. (1993). Another source (Scharf et al., 1995), which brings together "best practice" examples from eleven countries, explicitly includes rural community care examples.

Hospital Delivery of Home Care

In one tightly integrated hospital home care programme, home care is viewed as an extension of the hospital, which is considered responsible for home care (Mor et al., 1987). The “patients” served by this program are described as old and homebound, with multiple medical problems, in industrialized countries. The delivery of home care from hospitals is often viewed as a way to ensure the most appropriate use of restricted numbers of hospital beds. As fewer general or community hospital beds are being retained in the system, data about the use of these beds (Tomlinson et al., 1995) are needed to enable patients, caregivers and health professionals to use these reduced resources most effectively. Further, without specialized services in the community, demented elderly persons will become inappropriate patients in acute and long-stay hospital beds, especially in medical units (Hickey et al., 1997). One of the difficulties with hospital-based home care is that it is viewed primarily as acute care replacement and therefore, by definition, is less appropriate for chronically ill patients who require care in the community.

One article (Tolkoff-Rubin et al., 1978) demonstrates that hospital-based home care programs can truly be community care; the program described is administered by a national voluntary agency, on behalf of the hospital. This is an important example because it is a major deviation from the usual internal administration of hospital-based home care programs.

Health Care Planning

The most broad-ranging overviews of home care as a component of health care planning are those by Kalache and his colleagues (Kalache et al., 1998; Kalache et al., 1995). Three Canadian sources (Hollander et al., 1995; Havens, 1990; Havens, 1995a) describe how single point of entry systems in determine whether home care or residential care is more appropriate for the individual. The systems they describe operate with a single administration and use uniform assessments of the need for care, regardless of where that care is received.

In industrialized nations, service and planning models tend to emphasize the cost-effectiveness of home care. This is, at least in part, the result of a continuing scepticism about whether a relatively modest investment in home care can be truly effective. According to Browne and associates (1995), offering a complete proactive health program to chronically ill elderly persons in the early stages of their illness both increases well being and reduces the cost of services. Home care can be made more cost-effective (Weissert, 1990) by basing service planning on the characteristics of the target population. One of these characteristics leads to gender-specific modelling to predict levels and amounts of disability and hence the need for services (Lamb, 1997). Service modelling is an especially important strategy for increasing the cost-effectiveness of home care and other health services. Unfortunately, service modelling has seldom been undertaken in either home care research or program development. This is an area where additional research is clearly needed.

Community needs assessment surveys have been the basis for some home care planning. For example, surveys in China led to the conclusion that more capacity to provide

care at home is needed in the face of decreasing family size (Bartlett et al., 1997; Davis et al., 1995). Another survey (Factor et al., 1985) enabled the authors to project increased need for residential long-term care in Israel. There are large numbers of site-specific needs studies, but relatively few focus on home care and even fewer are sufficiently generic to enable replication. This is an area where assistance with research design would be useful.

A large number of articles focus on the planning process and outcomes. For example, Ishizaki et al. (1995) explain that obtaining physical, mental and socioeconomic information from new residents of a geriatric intermediate care facility enabled them to predict whether residents would be discharged to their own homes or remain in the facility for an extended period. One author (Togonu, 1985) reports that self-perceived health status was useful in planning health care utilization. Litwin (1997) used types of support networks to predict the level of service use. McWilliam and Sangster (1994) identified variation in quality of care outcomes between urban and rural areas, which has important implications for service planners. Another source (Matenga, 1994) recommends, based on the cost of care for terminal AIDS patients, that developing nations deliver care to these patients using nationally supported models of home care. Benjamin (1988), however, questions whether community-based home care models are appropriate to meet the great medical needs of AIDS patients.

Finally Jitapunkul et al. (1993) point out that data on disability and life expectancy are essential for health care planning, but they also note that these data are insufficient in many developing nations. Other authors (Yamamoto et al., 1992) describe the medical information system as an important component of the planning process in the community health care. They suggest that despite the problems encountered in implementing a medical information system, its importance to the planning process makes it an essential component of the system now.

CONCLUSION

There is a wealth of literature on some aspects of home care, much of it from Europe and North America, which has not been included here. It is hoped that the original sources cited here would be relatively easy to access. Readers who need specific information on selected aspects of this paper are encouraged to search the electronic data bases used to develop this paper and the related Annotated Bibliography.

The areas selected for discussion in this paper included home care policy, home care services, formal and informal caregiving in home care, home care for specific diseases, home care staffing and finally, home care as a component of the health care system. Each of these topics could easily be the subject of a paper in its own right; therefore, this document should be considered as an attempt simply to highlight the most relevant issues taken in the vast literature available. As noted periodically throughout the paper, the sources included here have been selected because they represent "best practices" that are most likely to be replicable or modified for application in many locations, regardless of the configurations of personnel and stage of development. This is not to suggest that any one example may simply be transplanted to another site; rather, these examples of best practices should stimulate local

thinking about how successes may be fostered and the likelihood of failures reduced. Clearly, new versions of these best practices will be endlessly variable and new examples that “fit” new settings will continue the progress of delivering care in the home and community. These new examples must be documented if others are to learn from them and the field is to continue progressing.

The policy sources presented here reflect the state of the fields of both policy analysis and home care and are largely descriptive. An important consideration in this area is that policy makers desire more information about home care than they are actually receiving, and they are more willing to use information in framing home care policies than is generally believed. Much of the policy material to date relates to caregiving, both formal and informal. The most important theme is the durability of informal caregivers in the home. This is accompanied, however, by a warning: caregivers must be supported if they are to continue providing care without becoming exhausted or health care consumers themselves. Formal care supports and complements but does not replace informal caregiving.

The home care services literature also tends to be descriptive. By and large, this literature describes innovations in services and service delivery, drawn almost exclusively from urban settings. This area of home care desperately needs documentation. Though those involved in delivering services may rightfully claim that they are too busy doing to write, the field must find ways to ensure that this documentation occurs.

As noted above, much of the home care literature deals with caregiving, especially informal caregiving. Two key aspects of informal care are family structures and community or neighbourhood networks, both of which support intergenerational caregiving, regardless of the direction of this support. As suggested in the policy summary above, informal caregiving support is essential to all home care and therefore is a major topic in the caregiving literature. The issue of whether or not to pay informal caregivers, and if so, at what rate and in what form is, as yet, unresolved in most countries. In this context the finding that informal care is not “free” care has been seldom reported.

Caregiving to victims of dementia is almost never included in the general caregiving literature, nor does the material on dementia caregiving usually include other kinds of caregiving. This separation in the literature comes from the perception that caregiving for dementia sufferers is qualitatively different from general caregiving. The same argument can be made about caregiving for persons with HIV/AIDS. While most of the “best practices” reported for HIV/AIDS care are site-specific they hold promise for adaptation to other locations and are generally appropriate to other diseases and forms of home care. For example, one source (Rossert et al., 1994) reports success in delivering home care to AIDS patients who live alone; this is a persistent home care issue and the success should be replicable with other diseases in a wide variety of locations. Likewise, the best examples of training indigenous, usually volunteer, caregivers are found in the HIV/AIDS literature and, again, should be emulated by home care programs generally. The lack of adequate knowledge about HIV/AIDS in many areas, the extremely rapid spread of the disease, and the lack of policy initiatives are all distressing; much more is known about HIV/AIDS than is being used either by potential victims or policy makers.

Home care staffing issues are largely, though not exclusively, issues of training the personnel who deliver home care, including informal and other voluntary caregivers. In the case of formal caregiving staff, the training is best undertaken as a multidisciplinary process and to the extent possible should include paraprofessionals and informal caregivers. Training has been identified as one of the most successful measures to improve retention rates among home care workers; therefore it is particularly disappointing that home care training occurs infrequently. Given the high incidence of injuries among home care workers, largely as a result of lifting clients, it is equally regrettable that training in body mechanics and lifting is not uniformly provided to caregivers. The limited amount of training time and material devoted to establishing and maintaining positive interpersonal relationships, so essential to good quality care, is also disappointing.

Adult day care and respite are two home care program components that are essential to enable informal caregivers to continue providing care without becoming exhausted. They're also the only congregate forms of care that are usually included in listings of home care services. For these programs, there are certain fixed costs regardless of whether the service is used by one or many clients at a time. Because the services are used intermittently and with highly individualized scheduling, they must be extremely flexible. Consequently, these services present more staffing challenges, although less delivery challenges, than other home care services.

Nursing personnel are usually identified as the major resource in formal home care programs, and they perform a wide variety of tasks and assume many roles in home care. These roles include assessment, case management, provision of needed services for chronic care and episodic acute care treatment, complex care for the most severely compromised home care clients, preventive care, collaboration with physicians, links to the broader health system, and monitoring informal caregiving.

Technology, especially "high" technology -- including information technology, will become more common in home care and the new technologies may be diffused even more rapidly in the developing world. It is crucial to ensure that appropriate training precedes and accompanies the adoption of "high" technology. There are ethical issues and quality of life issues that are relatively unique to "high" technology in home care. Policy makers as well as service personnel and the general public must address these issues if "high" technology solutions are to be viable in home care.

While most of this paper has addressed home care as a health care program in its own right, the final section discussed home care as a component of another part of the system. It is noteworthy that home care is generally poorly integrated into ambulatory care or community care. Yet, when home care is viewed as a component of hospital care, it is so tightly integrated into the hospital system that it is virtually impossible to identify where one ends and the other begins. The integration of home care into a comprehensive health care system is still very rudimentary. In the most industrialized nations, the driving force behind integration tends to be the need to increase or maintain the cost effectiveness of home care. Most examples of integration have resulted from community needs assessment surveys. Research

design assistance would make possible greater returns to planners with less investment of human and fiscal developmental resources.

This summary makes it clear that policy development is required in several areas, most specifically in relation to:

- supporting informal caregivers, by design not by default;
- explicitly endorsing the multidisciplinary and multifaceted training of home care personnel, including informal caregivers and clients;
- deciding whether or not to compensate informal caregivers and if so, how to do this;
- ensuring that the most vulnerable groups in the population are taken into account in health and home care policies;
- ensuring that rural and remote communities receive policy and program attention;
- encouraging the documentation of home care policy and experiences and the evaluation of home care programs;
- incorporating strategies based on health determinants in health policy development;
- addressing “high” technology in the home and, while remaining flexible,
- basing decisions on the best available evidence.

This summary also makes it clear that the training of home care personnel is largely inadequate and must be improved if home care is to remain viable with increasing demands, increasing complexity of care and diminishing informal support networks. Specifically,

- more training needs to be provided to home care clients and their informal support network members;
- training of professional and paraprofessional home care personnel needs to become more integrated and multidisciplinary;
- greater use of the “train the trainer” model is needed to expand the caregiver pool of indigenous home care personnel (but its effectiveness must be carefully monitored);
- training of formal home care workers should include skills training and training in establishing positive interpersonal relationships;
- training in the use of “high” technology, including information technology, is needed;
- all training needs to incorporate the importance of providing culturally sensitive and appropriate services, with particular attention to rural communities; and
- training in policy analysis, secondary data analysis and research methods is also sorely needed.

The success and long-term effect of any kind of training upon quality of care provided depends, however, upon adequate working conditions (e.g. payment, availability of necessary drugs, supplies and equipment, supportive supervision, transport, etc.)

Finally, this summary identifies a need for more or better research in a number of areas related to home care. We lack epidemiological data on women of all ages and dual caregivers demand attention. In addition, the following are urgently needed:

- home care policy analysis;
- home care program and service evaluations;
- determination of the impact of “high” technology on home care clients, their informal caregivers, and formal caregivers, and the potential “medicalization of the home”;
- research based on service modelling to increase the cost-effectiveness of home care;
- research on the long term health and economic impacts of caregiving; and
- secondary analysis of available data.

Developing greater uniformity in community needs assessments has the potential to increase the transferability of programs and make possible comparative analyses across multiple jurisdictions.

The ultimate goals of all home care are to provide appropriate and high quality care to individuals in the community and to support their caregivers, to enable both clients and caregivers to maintain their independence and the best possible quality of life. This paper points out what has been accomplished in home care around the world and suggests what still needs to be accomplished to make the goals of home care a reality, regardless of location, level of development or specific reason for home care.

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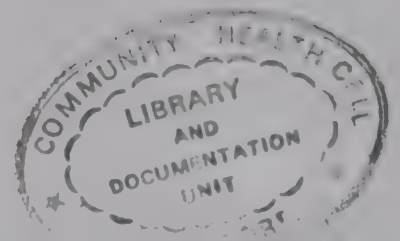
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